

Privacy in *Ethics and Ebola: Public Health Planning and Response*

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I. Introduction

In its report *Ethics and Ebola: Public Health Planning and Response* (*Ethics and Ebola*), the Presidential Commission for the Study of Bioethical Issues (Bioethics Commission) considered the privacy issues raised by the collection, use, and international sharing of biospecimens for research. The collection, use, and international sharing of biospecimens from the 2014-2015 Ebola epidemic in western Africa can help researchers track virus mutations and determine whether certain individuals are more susceptible to the disease. However, sharing biospecimens raises concerns about how best to protect the privacy interests of those whose biospecimens are shared—particularly when the biospecimens relate to potentially stigmatizing diseases. Another challenge to the collection, use, and international sharing of Ebola biospecimens is that Ebola biospecimens are collected from individuals undergoing clinical care; future use of those

biospecimens in research might require additional informed consent procedures, which could be challenging to obtain during a public health emergency.¹

II. Learning Objectives

After completing this activity, students should be able to:

1. Understand privacy concerns related to the collection, use, and sharing of biospecimens for research.
2. Describe ethical principles applicable to the collection, use, and sharing of biospecimens for research.
3. Discuss various approaches to protecting the privacy interests of persons whose biospecimens are shared.

III. Background

Sharing biospecimens, such as blood and tissue samples, that are collected during clinical care with biomedical researchers is critical for understanding disease, developing diagnostic and therapeutic agents, and translating research into clinical care. Sharing biospecimens raises important privacy issues for the individuals whose biospecimens are shared. Public health emergencies also give rise to privacy concerns unrelated to the sharing of biospecimens by virtue of the fact that individuals are exposed to serious diseases—information that could be stigmatizing if made public. In *Ethics and Ebola*, the Bioethics Commission recognized both the importance of sharing biospecimens and the associated privacy challenges, and endorsed ethical approaches to ensure that the privacy interests of persons whose biospecimens are shared are adequately protected.

A. Privacy and the Collection, Use, and Sharing of Ebola Biospecimens for Research

Biospecimens from patients with infectious diseases such as Ebola are generally shared in pursuit of two goals: first, to understand aspects of the virus itself (including whether and how the virus has mutated, how possible mutations might affect experimental treatments, and whether mutations affect the severity of the disease); and second, to understand more about human interaction with the virus (including the attributes that make a person more or less susceptible to

¹ Presidential Commission for the Study of Bioethical Issues (PCSBI). (2015, February). *Ethics and Ebola: Public Health Planning and Response*, Washington, DC: PCSBI.

the disease).² Progress toward the first goal involves looking to the genetic sequence of the virus itself to examine its viral qualities, including mutations, to shed light on the disease. Use of viral DNA does not reveal private or personal information about the person infected. Progress toward the second goal often requires access to and use of human genetic material and therefore presents challenges for protecting individual privacy.

Biospecimens from patients with Ebola that are shared for research to advance scientific knowledge could include blood products or other bodily tissues. Blood and tissue samples are made up of cells that contain the entire human genome. One key privacy concern is whether biospecimens that are shared are identifiable; that is, whether the genetic information alone or used in combination with other readily available information could be used to identify the individual from whom the biospecimen was obtained.³ Genomic sequences alone are not currently considered identifiable, even though the genomic sequence is unique to each individual. Accordingly, biospecimens that are shared and that contain genetic material might similarly not be considered identifiable. Biospecimens are, however, often shared along with certain identifiers—including the age, sex, and location of the person from whom the biospecimen was obtained—likely to make the shared biospecimens more useful to researchers and clinicians. These identifiers increase the possibility of rendering the biospecimens identifiable.

Concerns about identifiability and privacy are of particular interest when genetic material is involved. Genetic information has the potential to reveal powerful and fundamental information about an individual, including information about increased risk of genetic diseases such as breast cancer and Alzheimer's disease. Genetic information also can reveal information about biological relatives. Moreover, genetic information can reveal information about which the meaning is not yet known. For example, researchers might know that a particular genetic variant has been found in those with a propensity for heart disease, but might not yet know whether the variant causes the increased risk of heart disease. The discoveries derived from genetic material contained within the shared biospecimen might be ones that the person whose biospecimen was shared would prefer to keep private.

Sharing biospecimens raises additional privacy concerns, including the possibility of identifying characteristics of a tightly knit or geographically isolated group of individuals and revealing those characteristics to researchers from outside the community.

² Kolata, G. (2014, December 1). The virus detectives: Sifting through genes in search of answers on Ebola. *New York Times*, p. D1.

³ "Security and privacy," 45 C.F.R. §164.514(b)(1) (2002).

B. Guiding Ethical Principles

As described in *Ethics and Ebola*, ethical principles should guide consideration of the privacy concerns raised by the collection, use, and international sharing of biospecimens collected during public health emergencies. The principle of respect for persons recognizes the fundamental human capacity for rational self-determination and freedom from limitations that can prevent meaningful choice.⁴ The misuse or unauthorized disclosure of an individual's whole genome sequence data and information (the interpretation of the data) against the individual's expressed or considered wishes violates the principle of respect for persons.⁵ Accordingly, in *Ethics and Ebola*, the Bioethics Commission concluded that "the principle of respect for persons implies that biospecimens collected from persons exposed to Ebola should be covered by adequate privacy protections," and that "all persons who work with genetic and genomic data should be guided by professional ethical standards related to the privacy and confidentiality of such data."⁶ These protections are particularly important given the stigma often associated with infectious diseases.

Informed consent, a cornerstone of ethical research, is a fundamental way that researchers demonstrate respect for persons. However, obtaining informed consent for collecting and sharing biospecimens from patients with catastrophic infectious diseases such as Ebola is challenging because they are often severely ill and might be incapacitated and unable to consent. In addition, some patients might be minors and therefore unable to provide ethically and legally valid informed consent.

Other ethical principles help guide consideration of the privacy concerns surrounding the collection, use, and international sharing of biospecimens. These principles are discussed with regard to genomics in the Bioethics Commission's report [*Privacy and Progress in Whole Genome Sequencing*](#) (*Privacy and Progress*) and described at greater length in the "[Privacy Background Module](#)."⁷ The principles of public beneficence, responsible stewardship, and intellectual freedom and responsibility are of particular interest in the context of collecting biospecimens during an outbreak of an emerging or highly lethal infectious disease.

The ethical principle of public beneficence supports securing public benefits and minimizing public harms, including the individual harms that can result from scientific and technical

⁴ Beauchamp, T.L., and J.F. Childress. (2012). *Principles of Biomedical Ethics*, Seventh Edition. Oxford, UK: Oxford University Press; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1978). *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research* (DHEW Publication OS 78-0012). Washington, DC: Department of Health, Education, and Welfare. Retrieved February 10, 2015 from <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>.

⁵ Presidential Commission for the Study of Bioethical Issues (PCSB). (2012, October). *Privacy and Progress in Whole Genome Sequencing*, Washington, DC: PCSBI, p. 45.

⁶ PCSBI, (2015, February), op cit, p. 46.

⁷ This module is available at <http://bioethics.gov/node/4364>.

advances.⁸ Public beneficence requires that we collect biospecimens from individuals exposed to infectious diseases during public health emergencies, because it is the best and perhaps only time to advance research about those diseases. Public beneficence also recognizes that harms can befall communities—a notion that is particularly pertinent to the international sharing of biospecimens. Protecting the privacy of individuals whose biospecimens have been shared—and, by extension, the communities in which the individuals live—by, for example, anonymizing stored data, implementing information technology security protections, and limiting access and use can minimize or help prevent the harms that might occur in the event of a privacy breach.

The principle of responsible stewardship suggests that governments and societies should proceed prudently in promoting science and technology.⁹ The principle is most applicable to those who cannot represent themselves, including children, individuals with impaired consent capacity, or individuals who might be unaware of the risks of making particular decisions. Some of the individuals from whom biospecimens have been obtained in the 2014-2015 Ebola epidemic in western Africa likely fell into these categories, due to the severity of symptoms and the urgency of medical treatment. Accordingly, privacy protections are a prudential approach to following the principle of responsible stewardship.

Finally, the principle of intellectual freedom and responsibility grants scientists, acting responsibly, the right to use their creative abilities to advance science and the public good, and calls upon responsible parties to adhere to ethical ideals that include avoiding harm to others and abiding by applicable rules and regulations.¹⁰ The responsible parties in the context of a public health emergency such as an Ebola epidemic include researchers and clinicians responsible for collecting, using, and sharing biospecimens. Ensuring privacy protections is an important way to adhere to the ethical ideals set forth above and avoid harm to those from whom biospecimens have been obtained.

C. Privacy Protections for Biospecimens

Researchers, clinicians, and other professionals involved in the collection, use, and sharing of biospecimens collected from patients during public health emergencies should adopt and implement procedures to protect the privacy of those whose

“Without sufficient data, it may not be possible to assess and predict trends and risks in infectious diseases. It is acceptable to collect and use anonymized data for assessing and predicting trends in infectious disease without consent, as long as any invasion of privacy is reduced as far as possible.”

Nuffield Council on Bioethics. (2015, February 6). Comments submitted to the Bioethics Commission, p. 5.

⁸ Presidential Commission for the Study of Bioethical Issues (PCSB). (2010, December). *New Directions: The Ethics of Synthetic Biology and Emerging Technologies*. Washington, DC: PCSBI, pp. 24-25, 113.

⁹ Ibid, p. 25.

¹⁰ Ibid, p. 27.

biospecimens have been shared. One way of protecting individual privacy is by concealing the source's identity through anonymization or de-identification.

Anonymization is a process by which identifiable information is intentionally disguised or permanently removed; no link remains between individuals and their data.¹¹ When data associated with biospecimens is anonymized, clinicians, researchers, and others have no way of identifying the individual source. A second way of protecting privacy interests is by de-identifying the sample. The process of de-identification involves removing certain identifiers (including name, address, and personal identification numbers) in accordance with relevant regulations.¹²

When researchers use de-identified biospecimens, the research is not considered human subjects research and informed consent is not required.¹³ Moreover, because researchers' use of de-identified biospecimens is not considered human subjects research, the research is not required to undergo review by an institutional review board—a generally applicable safeguard that is no longer implemented once a biospecimen is de-identified.

In addition to anonymization and de-identification, individual privacy can be protected through data security procedures. These procedures, discussed at length in *Privacy and Progress*, “should guard against unauthorized access to, and illegitimate uses of, whole genome sequence data and information.”¹⁴ Ensuring that individuals whose biospecimens are collected during a public health emergency such as the Ebola epidemic receive adequate privacy protections requires that all persons and entities handling the biospecimens have adequate data security policies in place. For example, the National Institute of Health's (NIH) Genomic Data Sharing Policy mandates de-identification of data, review of informed consent processes regarding sharing for future use, and a tiered data distribution system.¹⁵

D. Bioethics Commission Recommendation

Of the seven recommendations the Bioethics Commission made in *Ethics and Ebola*, one addresses privacy directly. Recommendation 7 states that, in obtaining Ebola biospecimens, the U.S. government should ensure adequate privacy protections.

¹¹ PCSBI, (2012, October), op cit, p. 39.

¹² *HIPAA Privacy Rule*, 45 C.F.R. § 164.514(b)(2)(i).

¹³ *Protection of Human Subjects*, HHS. 45 C.F.R. § 46.101(b)(4).

¹⁴ PCSBI, (2012, October), op cit, p.5.

¹⁵ National Institutes of Health (NIH). (2014). National Institutes of Health Genomic Data Sharing Policy. Retrieved June 3, 2015 from http://gds.nih.gov/PDF/NIH_GDS_Policy.pdf.

Recommendation 7

The U.S. government should ensure that Ebola virus related biospecimens are obtained ethically, including addressing the challenges of obtaining informed consent during a public health emergency and ensuring adequate privacy protections. The U.S. government should also, in collaboration with partners, facilitate access to the benefits that result from related research to the broadest group of persons possible. This can be achieved by engaging in dialogue with global partners and working collaboratively with local scientists whenever possible to develop effective strategies for ensuring equitable distribution of the benefits of research both in the United States and abroad.¹⁶

IV. Reading

For the purposes of discussion, students should download and read the following Bioethics Commission materials (reports are available for download on the Bioethics Commission's website at www.bioethics.gov under "Projects"):

Ethics and Ebola: Public Health Planning and Response, pp. 43-51 ("Collection, Use, and International Sharing of Biospecimens for Research").

V. Discussion Questions

The following questions are based on the information provided above and through the indicated reading. They are intended to reinforce important considerations of privacy in the collection, use, and sharing of biospecimens for research that are highlighted in *Ethics and Ebola*. Important points are noted with each question to help the instructor guide group discussion. The "Additional Resources" section is a helpful source in answering these questions.

1. Why might biospecimens obtained from patients with Ebola be shared?

Starting points for discussion:

- a. Sharing biospecimens is fundamentally important to understand disease, develop diagnostic and therapeutic agents, and translate research into clinical care.
- b. Biospecimens obtained from patients with Ebola might be shared to understand the virus and how it causes disease (including whether and how the virus has mutated,

¹⁶ PCSBI, (2015, February), op cit, p. 50.

how possible mutations might affect experimental treatments, and whether mutations affect the severity of the disease).

- c. Biospecimens obtained from patients with Ebola also might be shared to understand more about human interaction with the virus (including the attributes that make someone more or less likely to be susceptible to the disease).

2. Why does the sharing of biospecimens obtained from patients with Ebola raise privacy concerns?

Starting points for discussion:

- a. Blood and body tissues are made up of cells each of which contain the entire human genome, a sequence that is unique to each individual.
- b. Biospecimens are often shared along with additional identifiers—including the age, sex, and location of the person from whom the biospecimen was obtained—that make the shared biospecimens more useful to researchers and clinicians, but also might render the biospecimens more identifiable.
- c. In the context of a public health emergency, such as the 2014-2015 Ebola epidemic in western Africa, in which biospecimens are collected primarily as part of clinical care when patients are severely ill, informed consent for the future research use of biospecimens might be particularly challenging to obtain.
- d. Diseases like Ebola can be stigmatizing for individuals who contract the disease, making adequate privacy protections particularly important.

3. What ethical principles guide consideration of the privacy concerns raised by the collection, use, and international sharing of biospecimens obtained from patients with Ebola?

Starting points for discussion:

- a. Respect for persons, which recognizes the fundamental human capacity for rational self-determination and freedom from limitations that can prevent meaningful choice. The misuse or unauthorized disclosure of an individual's genetic data and information against the individual's expressed or considered wishes violates the principle of respect for persons.
- b. Public beneficence, which supports securing public benefits and minimizing public harms including individual harms that can result from scientific and technical

advances. Protecting the privacy of individuals whose biospecimens have been shared can help satisfy the goal of minimizing or helping to prevent the harms of a potential privacy breach.

- c. Responsible stewardship, which calls on governments and societies to proceed prudently in promoting science and technology, with particular regard to those who cannot represent themselves. Privacy protections for those whose biospecimens were obtained—especially those who cannot represent themselves—would be a prudential approach to following the principle of responsible stewardship
- d. Intellectual freedom and responsibility, which grants scientists, acting responsibly, the right to use their creative abilities to advance science and the public good and calls upon responsible parties to adhere to ethical ideals that include avoiding harm to others.

4. How can researchers, clinicians, and other professionals protect the privacy of those whose biospecimens have been shared?

Starting points for discussion:

- a. Individual privacy can be protected by anonymizing or de-identifying the biospecimen:
 - i. Anonymization is a process by which identifiable information is intentionally disguised or removed.
 - ii. De-identification involves removing certain direct identifiers (including name, address, and personal identification numbers) pursuant to relevant regulations.
- b. Individual privacy can be protected through data security procedures. These procedures include guarding against unauthorized access to, and illegitimate uses of, genetic data and information.

VI. Problem-Based Learning

Scenario A. *A volunteer with an organization involved in the Ebola epidemic response in western Africa returns home to the United States and begins exhibiting symptoms of the disease. Upon entering his local hospital for suspected Ebola symptoms, the Centers for Disease Control and Prevention (CDC) requests that the patient's samples be transported from the local hospital to CDC headquarters in Atlanta. After CDC uses the sample to confirm the patient's Ebola diagnosis, his biospecimen and data might be used for future research.*

The following additional reading might be useful in considering this scenario:

National Institutes of Health (NIH). (2014). National Institutes of Health Genomic Data Sharing Policy. Retrieved June 3, 2015 from http://gds.nih.gov/PDF/NIH_GDS_Policy.pdf.

Privacy and Progress, pp. 36-39 (“Privacy Concerns Raised by Whole Genome Sequencing”). Available at <http://bioethics.gov/studies>.

Ybarra, M. (2014, October 24). Airforce transports doctor’s Ebola-infected blood sample from NY to CDC in Atlanta. *Washington Times*.

1. What privacy risks are posed by the transport of these biospecimens and how can they be minimized?

Starting points for discussion:

- a. Transporting biospecimens and their associated data pose privacy risks as they move from person to person. As the chain of custody grows, opportunities for mishandling—accidental or intentional—increase.
- b. At all stages, steps must be taken to minimize risk of a security breach and unauthorized access to data and to the biospecimen itself.
- c. Laws, regulations, and institutional policies help to minimize privacy risks involved in biospecimen collection and use. For example, the NIH Genomic Data Sharing Policy promotes responsible sharing of data from genomic research and protects privacy.

2. How do ethical principles apply to this scenario?

Starting points for discussion:

- a. Respect for persons recognizes the fundamental human capacity for rational self-determination and freedom from limitations that can prevent meaningful choice. In this scenario, the individual might not have been capable of providing fully informed consent for his samples to be used for research, especially for potential future research uses, when he required immediate medical treatment.
- b. Public beneficence requires that biospecimens are collected from individuals exposed to infectious diseases during public health emergencies, because it is the best and perhaps only time to advance research about those diseases. However,

implementing protections for individual privacy in this context is important to prevent the harms of a potential privacy breach.

3. What are some practical challenges for protecting individual privacy in this scenario?

Starting points for discussion:

- a. Ethical principles demand that biospecimens collected from persons exposed to Ebola be covered by adequate privacy protections, particularly because of the stigma associated with the disease. For example, some institutional policies require de-identification of biospecimens in order to protect individual privacy. However, in this case, it is difficult to completely de-identify the biospecimen because of the extremely low incidence of Ebola in the United States.
- b. It is challenging to de-identify biospecimens completely, especially in the context of genetic research, because biospecimens are often accompanied by medical and demographic information to make them more useful. In cases like this, even completely stripping data of any identifiers or demographic information would not protect the privacy of U.S. Ebola survivors and their families since their identities are often publicly known.

4. If the patient were to die from Ebola, what additional practical and ethical challenges might arise related to continued use and sharing of his biospecimens?

Starting points for discussion:

- a. U.S. research regulations do not recognize research on biospecimens from deceased individuals as constituting human subjects research, thus such biospecimens are not afforded typical research protections. While the patient is alive, the patient's consent might be required for certain research uses of the identifiable biospecimen. Once the patient has died, however, the biospecimen can be used in research without consent under the Common Rule. If the patient expressed wishes with regard to the biospecimen while alive, those wishes should nevertheless be respected after the patient's death.

Scenario B. *Global and national public health institutions are responding to an Ebola virus disease outbreak in western Africa. They are collecting biospecimens from infected individuals to be used for diagnosis and clinical care. These organizations also recognize the urgent need to conduct research to learn more about the disease and help treat it. To advance knowledge about the disease, biospecimens collected for diagnosis and clinical care might subsequently be used for research, including research conducted to assess the efficacy of survivors' blood as a*

treatment measure. Other research is conducted with the goal of developing new pharmacological interventions for prevention and treatment of Ebola.

The following additional reading might be useful in considering this scenario:

Mascalzoni, D., et al. (2014). International charter of principles for sharing bio-specimens and data. *European Journal on Human Genetics*, 1-8(23), 721-728.

1. How should the organizations collecting the biospecimens design informed consent processes and forms to ensure ethical collection and research use of biospecimens?

Starting points for discussion:

- a. Given that biospecimens obtained from patients with Ebola are only available from infected individuals, a public health emergency is often the best and perhaps only time to advance research. Therefore, such biospecimens are valuable and must be collected ethically under particularly challenging circumstances. When designing informed consent processes and documents, researchers must be mindful that during an emergency, individuals might be less likely to read provided information or consider all risks involved, including privacy risks.
- b. Informed consent processes must make clear to individuals what protections will be in place to protect their privacy. Conveying privacy protections during the informed consent process might be particularly challenging in the context of a public health emergency when patients are severely ill, and in relation to cultural and other contextual factors that might affect an individual's willingness to consent to collection, use, and sharing of biospecimens for research.

2. What measures should researchers take to protect privacy when collecting biospecimens?

Starting points for discussion:

- a. All persons and entities handling biospecimens must have adequate data security policies in place. For example, the NIH's Genomic Data Sharing Policy seeks to provide protections for research involving human data.
- b. Because of the resource-intensive nature of collection and testing of biospecimens, much of the work must be performed in institutions that have highly developed laboratory infrastructure. Accordingly, research on Ebola biospecimens often is conducted in countries not affected by the outbreak, requiring international transport,

which might present challenges to establishing consistent privacy protections. Thus, international bodies and organizations should collaborate to ensure a consistent floor of privacy protection across borders regardless of where and how biospecimens and data were obtained.

VII. Exercises

Exercise A. *While caring for a patient infected with Ebola, a nurse working in the United States began exhibiting symptoms of the disease. On her way to the emergency room, she called and asked the hospital to not reveal her identity because she did not want people to know she had Ebola. The hospital revealed not only her name, but, without her permission, released a video of her undergoing care.*

The following references provide a summary of these events and privacy concerns for the nurse:

Nina Pham v. Texas Health Resources, Inc., Brief for the Petitioners no. DC-15-02252. (2015).

Emily, J. (2015, March 3). Texas Health responds to two claims in Ebola nurse Nina Pham's suit. *Dallas Morning News*.

1. **What privacy concerns might the nurse have had when the hospital released her identity and video?**
2. **What ethical principles should guide hospital staff members who have access to private and potentially stigmatizing medical information related to the public's health?**
3. **What laws and regulations might have protected the nurse from these privacy violations? Are these protections sufficient?**
4. **How might the media responsibly communicate what the public needs to know about an evolving public health emergency without violating individual privacy?**
5. **Devise a privacy policy for the hospital, and particularly for employees involved in the care of patients likely to be of interest to the media, reflecting applicable ethical principles and legal considerations.**

VIII. Glossary of Terms

Anonymized data: Data from which a patient's identifiers have been permanently removed and no link remains between the individual and his or her data.

Autonomy: The capacity to direct the course of one's own life or to live according to one's own values and beliefs.

Biobank (biorepository): A stored collection of physical biological samples (e.g., blood or tissue); some biobanks also store associated data (e.g., medical information).

Common Rule: Current federal regulations that protect research participants, codified by the U.S. Department of Health and Human Services in the Code of Federal Regulations at 45 C.F.R. Part 46, Subpart A. Also known as "Human Subjects Regulations."

Confidentiality: A set of rules or a promise to restrict access to certain information.

De-identified data: Data that have been separated from information identifying the individual from which they were derived. Importantly, a "key" or code connecting the two might still exist, but researchers are not allowed to access the key.

Informed consent: The process of informing and obtaining permission from an individual before conducting medical or research procedures or tests.

Intellectual freedom and responsibility: The notion that scientists and other researchers, acting responsibly, should use their creative abilities to advance science and the public good while adhering to the ideals of research, avoiding harm to others, and abiding by all associated rules.

Large-scale genetic sequencing: The ordering of the billions of base pairs—the As, Ts, Cs, and Gs—that make up our genetic code (e.g., whole genome sequencing, whole exome sequencing, and other next-generation genomic analyses).

Public beneficence: An ethical principle that encourages us to pursue and secure public benefits while minimizing personal and public harm.

Respect for persons: Ethical principle requiring that individuals are treated as independent and self-determining (autonomous) agents and that persons with diminished autonomy are entitled to additional protections.

Responsible stewardship: The act of ensuring and/or promoting consideration of the interests and needs of those not in a position to represent themselves in social discourse.

Whole genome sequencing: Determining the order of nucleotide bases—As, Ts, Gs, and Cs—in an individual's entire DNA sequence.

IX. Additional Resources

Centers for Disease Control and Prevention. (2015, January 30). Interim guidance for specimen collection, transport, testing, and submission for persons under investigation for Ebola virus disease in the United States. Retrieved from <http://www.cdc.gov/vhf/ebola/hcp/interim-guidance-specimen-collection-submission-patients-suspected-infection-ebola.html>.

Chen, D.T., et al. (2005). Research with stored biological samples: What do research participants want? *Archives of Internal Medicine*, 165(6), 652-655.

Elbe, S. (2010). Haggling over viruses: The downside risks of securitizing infectious disease. *Health Policy and Planning*, 25(6), 476-485.

Emily, J. (2015, March 3). Texas Health responds to two claims in Ebola nurse Nina Pham's suit. *Dallas Morning News*.

Eserink, M. (2015). Risk of exposure: When new or dangerous infectious diseases strike, public health often trumps personal privacy. *Science*, 347(6211), 498-500.

Fidler, D.P. (2008). Influenza virus samples, international law, and global health diplomacy. *Emerging Infectious Diseases*, 14(1), 88-94.

Fidler, D.P. (2010). Negotiating equitable access to influenza vaccines: Global health diplomacy and the controversies surrounding avian influenza H5N1 and pandemic influenza H1N1. *PLoS Medicine*, 7(5), e1000247.

Gostin, L.O., et al. (2014). Virus sharing, genetic sequencing, and global health security. *Science*, 345(6202), 1295-1296.

Mascalzoni, D. et al. (2014). International charter of principles for sharing bio-specimens and data. *European Journal of Human Genetics*, 2014, 1-8(23), 721-728.

National Institutes of Health (NIH). (2014). National Institutes of Health Genomic Data Sharing Policy. Retrieved June 3, 2015 from http://gds.nih.gov/PDF/NIH_GDS_Policy.pdf.

Nina Pham v. Texas Health Resources, Inc., Brief for the Petitioners no. DC-15-02252. (2015).

Tindana, P., et al. (2014). Ethical issues in the export, storage, and reuse of human biological samples in biomedical research: Perspectives of key stakeholders in Ghana and Kenya. *BMC Medical Ethics*, 15, 76.

Upshur, R.E.G., J.V. Lavery, and P.O. Tindana. (2007). Taking tissue seriously means taking communities seriously. *BMC Medical Ethics*, 8, 11.

Ybarra, M. (2014, October 24). Airforce transports doctor's Ebola-infected blood sample from NY to CDC in Atlanta. *Washington Times*.

Zhang, X., et al. (2010). Attitudes towards transfers of human tissue samples across borders: An international survey of researchers and policy makers in five countries. *BMC Medical Ethics*, 11, 16.